PREVALENCE OF DEPRESSION AMONG FAMILY CAREGIVER OF DISABLED CHILDREN ATTENDING REHABILITATION CLINIC IN DAMMAM, SAUDI ARABIA

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Master's Dissertation to obtain the Master's Degree in Primary Care Mental Health

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ABSTRACT

BACKGROUND: According to national statistics, there is 667 thousands individuals with disability in Saudi Arabia, with approximately 56% of them are children under the age of 15 years. Although family caregiving is the most common form of caregiving in Saudi Arabia, there is limited local data that assess the psychological impact of providing caregiving for family members with disability.

OBJECTIVE: To estimate the prevalence and the predictors of depressive and anxiety symptoms among caregivers who are providing caregiving for family members with disability at primary care setting.

METHODS: Observational cross-sectional study has been conducted between April and October 2017 among caregivers who are providing caregiving for family members with disability at two rehabilitation clinics in Dammam and Al-Khobar, Saudi Arabia. Data collection was done using a structured questionnaire which included socio-demographic and clinical characteristics of the caregiver and his/her family member with disability. Caregivers' depressive and anxiety symptoms were assessed using the 9-item Patient Health Questionnaire (PHQ-9) and the 7-item Generalized Anxiety Disorder (GAD-7) questionnaire, respectively.

RESULTS: A total 93 caregivers have been included in the current analysis. The majority of caregivers were married (92.4%), females (97.8%), with an average age of 35.1±8.7 years. The majority of family members with disability were males (70.7%), children (87%), with an average age of 10.2±13.1 years. On average, caregivers were providing caregiving for 6.0±5.7 hours per day for approximately 5.5±3.6 years. The average PHQ-9 score was 4.3±2.7 points and the average GAD-7 score was 4.1±3.0 points. Considering the clinical cutoff point (i.e. PHQ-9 or

GAD-7 ≥10), the prevalence was 1.1% for depression, 2.2% for anxiety, and 2.2% for depression or anxiety combined. Including mild depression or anxiety (i.e. PHQ-9 or GAD-7 ≥5), the prevalence was 54.8% for depression, 43.0% for anxiety, and 59.1% for depression or anxiety. In multivariate analysis, the caregiver feeling that family member with disability represent a source of stress for the family was the only independent predictor for the presence of depression or anxiety (even of mild degree) among caregivers.

CONCLUSIONS: The findings of the current study revealed mild degree of depression and anxiety among caregivers (mainly mothers) who were providing caregiving for family members with disability (mainly their children) and attending one of two rehabilitation clinics at the Eastern Saudi Arabia. Considering the clinical cutoff point, the current prevalence rates seem much lower than the rates reported internationally. While it is difficult to give a definitive explanation, the difference may reflect cultural and other healthcare differences. Further studies are required to confirm the current finding and to answer several other related questions.

INTRODUCTION

I. Definition of disability:

The World Health Organization (WHO) defined disability as difficulties encountered in one or more of the functioning areas, which leads to impairments, activity limitations and participation restrictions [1, 2]. Disability according to this definition is the interaction between individuals with a health condition (e.g. cerebral palsy or Down syndrome) and personal and environmental factors (e.g. negative attitudes or limited social supports). The US Centers for Disease Control and Prevention (CDC) defined disability as any condition that makes it more difficult for the person with that condition to do certain activities and interact with the world around them [3]. The main categories of disability are physical, sensory, psychiatric, cognitive and intellectual; with many people with disability have more than one type of disability on the same time [2]. The official Saudi definition for a person with disability is an individual who suffers a physical or mental impairment that makes it difficult to successfully carry out business or physical and mental activities which might be made by normal persons [4].

II. Global burden of disability:

Global aging seen in different parts of the world combined with the increasing prevalence of chronic diseases, which are the largest contributor to the years lived with disability (YLDs), resulted in net increase in the number of people with disability [5]. According to the WHO, over a billion people (15% of the world's population) have some form of disability. Of them, 93 million children and 110-190 million adults (>15 years) have significant difficulties in functioning [1, 2]. A meta-analysis of 52 studies done in different parts of the world estimated the prevalence of intellectual disability at 10.37 per 1000 population [6]. Interestingly, the prevalence

was considerably higher among children and studies done in low and middle income countries [6]. The global prevalence of hearing impairment among children aged 5-14 years has been estimated at 1.4% [7]. Additionally, the global age-standardized prevalence of blindness has been estimated at 1.9% while moderate/severe vision impairment at 10.4%, accounting for 32.4 million blind individuals worldwide and additional 191 million individuals with moderate/severe vision impairment [8]. In the US, the most common types of disability among children are attention-deficit hyperactivity disorder (ADHD), autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, learning disability, and vision impairment [9]. On the other hand, the most common types of disability among US adults are mobility disability, cognitive disability, and sensory disability [10].

III. Saudi burden of disability

In Saudi Arabia, there are very limited data on the prevalence and incidence of disability, mainly due to cultural difficulties associated with conducting this type of research [11]. For example, some people feel ashamed of having a disable family member and tend to avoid participation in research as disability in the mind of these people is associated with low quality of life, poverty, helplessness, and dependence [12]. According to the Saudi General Authority for Statistics, there is 667 thousands individuals with disability in Saudi Arabia, with approximately 56% of them are children under the age of 15 years. This represents an overall prevalence of 3.3%, which range between 1.9 in children <4 years to 27.6% among older adults >80 years. The most common types reported were physical (37%), vision (36%), hearing and communication (21%), mental (4%), and others (1%). The frequent cause of disability in Saudi Arabia as perceived by the family was hereditary diseases followed by childhood illnesses [13]. The risk factors frequently associated with disability among Saudi families as reported in epidemiological

studies include early- and late-age marriage or childbearing, multi-parity, consanguineous marriages, illiteracy, and unemployment [14, 15].

The prevalence of disability was estimated in cross-sectional studies among Saudi children between 3.7% and 4.7%, with speech, motor and mental disabilities are the most common types [13, 16]. The prevalence of different types of disability was variable in different studies. For example, a cross-sectional study done in Riyadh estimated the prevalence of hearing impairment at 1.75% among pre-school children, with the majority having conductive deafness in both ears [17]. Another cross-sectional study done in Qaseem estimated the prevalence of physical disability among children at 1.7% and mental retardation at 1.4% [18]. Additionally, a population-based national survey estimated the prevalence of mental retardation at 0.89% among Saudi children less than 18 years, with the majority having moderate to severe mental retardation (71%) and not attending school (83%) [19]. On the other hand, adults above 15 years who represent 85% of the patients attending rehabilitation center in Saudi Arabia have traumatic physical disability as the most common type [20].

IV. Impact of disability on the family

Family has a key role in providing caregiving for family members with disability, specially when social and community support is not optimum [21, 22]. Providing caregiving for a family member with disability (typically a child) place a substantial burden on the whole family, which acts in multiple roles and take on additional duties [23, 24]. While some families establish strong coping mechanisms, some fail to cope and end up suffering from heightened levels of stress and burnout [22, 25]. Stressors that are frequently faced by the families providing caregiving for family member with disability include substantial financial, emotional, psychological, social struggles [26]. These stressors reflect the amount of time and responsibilities dedicated to

caregiving role as well as the strain from marital and family pressures [26]. Mothers of disabled children, specially mental retardation, may suffer from more depression and spousal problems, while she is acting as the prime lifelong caregiver [27]. It was found that involving the father in providing caregiving for disabled child can considerably alleviate the mother stress [28]. Several interventions have been suggested to target the stress in families providing caregiving for family members with disability to improve caregivers' sleepiness, mental, and physical health [29, 30]. These interventions are believed to positively impact the caregiver as well as the outcome of caregiving [30].

V. Psychological problems among caregivers

Long term caregiving may lead to strain for caregivers. For example, a review of a number of studies showed that between 12% and 49% of mothers providing caregiving for children with epilepsy had depressive symptoms [31]. Similarly, in a Swedish study, up to 50% of parents providing caregiving for children with intellectual disability had depressive symptoms compared to 15-21% in control families [32]. Additionally, a study among mothers of children with learning disability showed that 25.5% of the mothers had anxiety and 10.4% had depression [33]. Moreover, several studies showed that families providing caregiving for adult patients with different disabling diseases suffer from high levels of distress, reduced quality of life, and even psychiatric disorders among the caregivers [34-36]. It has been shown that the presence of depressive symptoms in mothers can negatively impact the child outcomes, including behavior problems and health-related quality of life [31]. Similarly, depression among caregivers of adult patients with stroke has been shown to correlate with depressive symptoms develop in disabled adults after stroke [37]. Several programs have been described to increase the coping and to

reduce the psychological impact of caregiving [38-40]. Caregiving for older adults has been well researched, and professionals, especially those in the Alzheimer's field, are increasingly aware of the stress and burden involved in caregiving situations

Although family caregiving is the most common form of caregiving in Saudi Arabia, there is limited local data that assess the psychological impact of providing caregiving for family members with disability [41, 42]. We were able to identify two studies that compared the levels of depression or anxiety among family caregivers compared with control groups [41, 42]. Additionally, another two studies examined alexithymia and dissociative experiences among mothers providing caregiving for children with disability [43, 44]. However, none of these local studies primarily focused on estimating the prevalence of either depression or anxiety nor were done at primary care rehabilitation setting. Moreover, comprehensive list of caregiving-related predictors of depression and anxiety using univariate and multivariate has never been examined.

VI. Factors affecting psychological problems among caregivers

Several studies done outside Saudi Arabia examined the impact of parents' characteristics and sometimes disabled child characteristics and the development of maternal depressive symptoms. For example, a review of a number of studies among mothers providing caregiving for children with epilepsy showed that maternal depression was associated with the mother role ambiguity, worry, satisfaction with relationships, and lower education [31]. Additionally, maternal depression was associated with the presence of comorbidities and behavior problems (specifically, attention deficit hyperactivity) in children with epilepsy [31]. Similarly, maternal depression among mothers providing caregiving for intellectually disabled children was

associated with maternal neuroticism, lower education levels, insufficient income, family problems, and being a single mother [32, 45-47].

Unlike depression, anxiety among mothers providing caregiving for children with disability received little attention. In a study done among mother providing caregiving for children with hearing problems, it was found that anxiety state and trait levels were positively correlated with the overall and almost all subscales of family needs survey (including need for information, help explaining to others, community services, financial assistance and family functioning) [48]. In another study, anxiety and depression among mothers of infants with perinatal brachial plexus injury were associated with the recovery status of their children but not the severity of brachial plexus injury [49].

Status Loss and Discrimination

Link and Phelan propose that stigma is enacted upon individuals when labeling, stereotyping, and separation lead to acts of commission or omission on the part of others that impose limits on the social participation of stigmatized individuals. Perhaps the greatest concern among research participants is that the separation imposed by the reactions of others will interfere with the ability to establish stable, loving romantic partnerships.

Rehabilitation and intervention services for disability

Disabled person has special needs that include health, educational, rehabilitation, social, and support services. Rehabilitation are set of measures that assist individuals with disability to achieve and maintain optimal functioning in interaction with their environments [50]. Rehabilitation services can be provided in hospitals (medical rehabilitation for acute onset conditions), specialized centers (follow-up medical rehabilitation, therapy, and assistive devices), and in the community (longer-term rehabilitation provided at primary health care centers and home-care therapy services) [2].

Form the healthcare perspective, children with disability accounts for a substantial proportion of health care costs due to multiple admissions, longer hospital stay, frequent re-admission, and the need for extra home care and physician services [51]. This increases the pressure on already stretched healthcare system, specially with children with multiple disability [51]. Therefore, it has been suggested that provision of a well-structured outreach community programs may be associated with a greater improvement in functionality and better satisfaction and compliance with services, specially in a resource-constrained context [52].

In Saudi Arabia, close to 80% of the healthcare system is covered by the government and primary care services represent more than 75% of the visits to governmental facilities [53]. Health care system in Saudi Arabia faces multiple challenges, such as shortage in national health professionals, poor referral system, and the high utilization of free services [53, 54]. To face these challenges, the Saudi Ministry of Health has been focusing on preventive and rehabilitative services [53]. Therefore, the Saudi Ministry of health started several rehabilitative programs over the last 2 decades targeting persons with disability [11]. The offered programs included physical, occupational, speech and hearing therapy as well as prosthetic and orthotic services [11]. Additionally, home care program was expanded to minimize the cost and the duration of stay at rehabilitation centers [20]. However, it has been estimated that the available rehabilitation services are still unable to cover the large number of disabled individuals in Saudi Arabia [11]. The presence of local rehabilitation services, specially of multidisciplinary natures, have been shown to significantly improve the overall dependency and functional performance of the disabled individuals [55].

VII. Significance and rational of the study

Despite the growing community awareness about disability, limited research has been done in Saudi Arabia to quantify the burden and impact of disability [11, 20]. Although long term caregiving can cause substantial strain to caregivers, there is limited research done in Saudi Arabia to quantify the psychological impact of providing caregiving for family members with disability [41, 42]. Additionally, none of these local studies primarily focused on estimating the prevalence of either depression or anxiety nor were done at primary care rehabilitation setting. Estimating the prevalence of psychological problems among caregivers is critical for planning and implementation of any future intervention programs [38-40]. Additionally, determining the socio-demographic characteristics associated with psychological problems among caregivers may help targeting those who are in desperate need for help.

AIM OF THE STUDY

The current research was done to basically answer two important questions as regards family caregiving, which is the most common form of caregiving in Saudi Arabia; (1) What is the burden of depressive and/or anxiety symptoms among those providing caregiving for family members with disability? (2) What are the factors predicting the presences of depressive or anxiety symptoms among these caregivers? Therefore, the current study has the following objectives:

1. To estimate the prevalence of depressive and anxiety symptoms among caregivers who are providing caregiving for family members with disability attending rehabilitation clinics at primary care centers in Dammam and Al-Khobar, Saudi Arabia
2. To determine the socio-demographic characteristics associated with depressive and anxiety symptoms among the above caregivers, including those related to the caregivers and family members with disability

METHODS

Design:

Observational cross-sectional study has been conducted during April and October 2017 among caregivers who were providing caregiving for family members with disability.

Setting:

The study was conducted at the rehabilitation clinics at ibn Rushed primary care center in Dammam and Al-Doha primary care center in Al-Khobar, Saudi Arabia. Both rehabilitation clinics provide services to approximately 180 children and adults with disability. The underlying conditions served at both clinics include hearing/speech problems, Down syndrome, mental problems, ADHD, developmental problems, cerebral palsy, multiple congenital anomalies, and other conditions. Each clinic is staffed by one physician and two nurses. The average number of patients served per day is approximately 7. The caregivers are given instruction and life training on how to take care with their family members with disability at home. The nurses are also available after hours by phone and sometimes do home visits.My role was conducting this quetioneers to the rehabilitation team work who take care and deal with my target caregivers

Subjects:

The current study targeted caregivers who were providing caregiving for family members with disability at a primary care rehabilitation setting in Saudi Arabia. The selection criteria were as follow;

Inclusions:

- Adult caregivers who were providing caregiving for family members (aged 1 to 60 years) with disability and attending the rehabilitation clinics at ibn Rushed primary care center in Dammam and Al-Doha primary care center in Al-Khobar
- Both male or female caregivers were included

Exclusions:

- Caregivers with disability
- Caregivers with multiple severe comorbidity including cancer and/or organ failure
- Caregivers diagnosed with depression or anxiety before staring the care of the current family member with disability

Sample size estimation:

The prevalence of depressive and/or anxiety symptoms among caregivers who were providing caregiving for family members with disability have been estimated variably in different studies done outside Saudi Arabia, ranging between 10% and 50% [31-33]. In Saudi Arabia, the actual prevalence was not estimated but the levels of depression and anxiety are generally lower than seen internationally [41, 42]. Assuming an average prevalence of depressive and/or anxiety symptoms of 15% with two-sided confidence limits of 5%, **95** caregivers were estimated to be required for interview (out of the 180 population served in both clinics), using 80% power level and 95% two-sided significance level. The equation used was

$$N = \frac{Z^2_{\alpha/2} * P * (1-p) * D}{E^2}$$

$Z_{\alpha/2}$: is normal deviate at a level of significance=1.96

P: is the hypothesized prevalence of depressive and/or anxiety, which was set at 15%

E: is the desired precision (half desired CI width), which was set at 5%

D the design effect, which is usually set to 1 in cross-sectional studies

Sampling technique:

Caregivers were recruited conveniently while accompanying their family member with disability at the rehabilitation clinics at primary care centers in Dammam and Al-Khobar. Eligible caregivers who agreed to join the study and provided informed consent were included in the study. The study objectives and requirements were explained to the caregiver before signing the consent (Appendix-I). The consent was required to be signed before filling the questionnaire (Appendix-II). The researcher was responsible for recruitment, explaining the objectives of the study, obtaining the consent, and collecting the filled questionnaire.

Data collection tools:

Data collection was done using a structured study questionnaire, which included data on socio-demographic and clinical characteristics of the caregiver and his/her family member with disability (Appendix-II). The questionnaire was developed in English but Arabic copies were given to the examined caregivers. The questionnaire was self-administered. However, assistance was provided for caregivers who cannot read or need otherwise assistance. The total duration required to answer the questions of the study questionnaire was on average 20 minutes. The following variables were collected:

- Caregiver: age, gender, nationality, marital status, educational level, occupation, family income, type of residence, relation to the family member with disability, comorbidity, and medical care

- Family member with disability: age, gender, nationality, type, duration, and severity of disability, comorbidity, and medical care
- Caregiving: years, hours per day, shared caregiving, other caregiving responsibilities, other family members with disability or psychiatric diseases, rehabilitation care, assistive devices, and social support
- Impact on caregiver: family stress, work, travel, entertainment, and intimidation

The Arabic version of the 9-item Patient Health Questionnaire (PHQ-9) [56] was used to assess the presence of depression (Appendix-III) among the caregivers and the 7-item Generalized Anxiety Disorder (GAD-7) questionnaire [57] was used to assess the presence of anxiety (Appendix-IV).

Validation of data collection tools

1. The face (how much questions cover the study objectives) and content (scientific merit of questions) validity of the study questionnaire were evaluated by a rehabilitation consultant and a family medicine consultant. The questionnaire was slightly modified based on the expert suggestions.
2. The Arabic version of the questionnaire was developed by translating the English questionnaire by bilingual reviewer. This was back translated into English by another bilingual reviewer, and comparison was done to confirm its validity. Minor discrepancy between the original English version and the back-translated version was resolved with the help of a third bilingual reviewer

3. A pilot study was conducted on a sample of 5 caregivers with very positive feedback. This pilot study was used to test the clarity and validity of data collection tool, to test the logistics of data collection, and to estimate the duration of data collection.
4. For the Arabic version of both PHQ-9 and GAD-7, no further validation was done as they have been already validated before [58, 59].

Outcome definitions:

Depression was assessed using the PHQ-9 score and anxiety was assessed using the GAD-7 score. Every item of the PHQ-9 and GAD-7 was given "0" if the caregiver answered "not at all", "1" if the caregiver answered "several days" ,"2" if the caregiver answered "more than half the days", and "3" if the caregiver answered "nearly every day". The total score was calculated by summing the scores of all respective items. The maximum score is 27 (9*3) for PHQ-9 and 21 (7*3) for GAD-7. Categorizing of the PHQ-9 score [60] and GAD-7 score [57] were done according to reported standards, as shown below

	PHQ-9 for depression	**GAD-7 for anxiety**
No or minimal	0-4	0-4
Mild	5-9	5-9
Moderate	10-14	10-14
Severe or moderately severe	15-27	15-21

Ethical considerations:

The following ethical consideration were taken into consideration during conducting this research

- The proposal was approved by the research ethics committee at the Saudi Ministry of Health.

- Caregivers were requested to sign the consent (Appendix-I) after explaining the objectives and requirements of the study and before filling the questionnaire.
- Signing the consent was considered as acceptance of participation
- Acceptance of participation was a completely voluntary process
- No incentives or rewards were given to the caregivers
- Caregivers had the right to contact the researcher for any query and to withdraw at any time without any obligation towards the study researcher or the rehabilitation clnic
- The data collected were confidentially kept in a safe place and data were only used for the purposes described in the study objectives
- Sensitive caregiver information including name, national ID, date of birth, and contacts were not collected and the analysis was done anonymously

Statistical analysis:

The questionnaires was coded and the collected data were entered into excel file. SPSS software (release 24.0, Armonk, NY: IBM Corp) was used for all statistical analyses. All P-values were two-tailed. P-value <0.05 was considered as significant. Data were presented as mean and standard deviation (SD) for continuous variables (such as age and duration of caregiving) and frequency and percentages for categorical variables (such as gender and occupation). Scores were calculated for PHQ-9 and GAD-7 with the maximum score 27 for PHQ-9 and 21 for GAD-7. Categorizing of the PHQ-9 score and GAD-7 score were done according to reported standards as mentioned above [57, 60]. The characteristics of the caregivers, caregiving, and family members with disability were compared between caregivers who have and those who do not have depression and/or anxiety. Since only two caregivers had depression or anxiety as per the clinical cutoff points, it was decided to include mild depression to create convenient groups. Chi-square

or Fisher's exact tests, as appropriate, were used to test for significant differences in categorical data while t-test or Mann-Whitney U test, as appropriate, were used to test for significant differences in continuous data. Multivariate logistic regression analysis was used to detect independent associations between the presence of depression and/or anxiety among the caregiver and the characteristics of caregivers, caregiving, and family members with disability.

RESULTS

A total 93 caregivers have been included in the current analysis. Table 1 shows the socio-demographic and clinical characteristics of the included caregivers. The age ranged between 21 and 60 years with an average age of 35.1±8.7 years. Approximately 44.0% of the caregivers were between the age of 30 and 40 years. The vast majority of caregivers were females (97.8%), Saudi nationals (84.9%) and married (92.4%). Approximately 39.6% of the caregivers had education above high school and 33.0% had education below high school. The majority (81.5%) of caregivers were housewives or unemployed, with only 17.4% were working mainly as governmental employees. Approximately 38.7% of the caregivers had family income between 6,000 and 9,999 SR per month, with 30.1% had income below 6, 000 SR and 31.2% had income equal or above 10,000 SR. The most frequent type of caregivers' residence was renting (52.2%), followed by owning a house (45.7%) and having employer-provided housing (2.2%). On average, caregivers were living with 5.9±2.3 family members in approximately 6.3±2.3 rooms. Only 10.8% of the caregivers had chronic diseases, mainly hypertension and diabetes. The majority (65.9%) of caregivers had no regular medical checkup. The majority (60.9%) of caregivers had regular social activities such as gem, salon, social visit, or football match. The vast majority (93.5%) of caregivers were parents of family member with disability.

Table 2 shows the socio- demographic and clinical characteristics of the family members with disability. The majority (87.0%) of family members with disability were children, with an average age of 10.2±13.1 years. Approximately 44.6% of family members with disability were pre-school children (under 6 years) and 42.4% were school children (between 6 and 15 years). The majority of family members with disability were males (70.7%) and Saudi nationals (85.9%).

The birth order of family members with disability among their siblings was on average 3.4±2.7. Approximately half (49.5%) of family members with disability had parents' consanguinity. The most frequent types of disability were mental/intellectual disability (40.9%) and speech/hearing disability (37.6%), followed by physical (5.4%), psychiatric (5.4%), multiple (3.2%), vision (2.2%), and other (5.4%) disabilities. The average duration of disability was 6.4±7.8 years. The majority of family members with disability had moderate level of disability (59.8%) with no other disease (86.8%). Approximately half (49.5%) of family members with disability had regular medical checkup, with approximately 58.2% had easily accessible medical services.

Table 3 shows the characteristics of caregiving and its impact. On average, caregivers were providing caregiving for 6.0±5.7 hours per day for approximately 5.5±3.6 years. The majority (82.6%) of caregivers were providing caregiving for a single family member. In 17.4% of the cases, another family member needed assistance mainly due to disability (73.3%), old age (20.0%), or chronic disease (6.7%). The majority (88.0%) of caregivers had another family member who helped in providing caregiving for the family member with disability. Approximately 59.3% of family members with disability were regularly receiving rehabilitation care services. The majority of caregivers had good communication with attached doctor or nurse (85.7%) but not with attached social workers (96.6%) at the rehabilitation center. Only 7.9% of family member with disability were regularly receiving assistive devices, mainly in the form of hearing aids, wheelchairs, and glasses. 'the majority (69.9%) felt able to stop or control worrying'. Approximately 58.4% of family member with disability were involved in recreational activities. The majority of caregivers thought that family members with disability represent a source of stress for the family (58.9%) and affect their ability to travel, work, or entrain (70.3%).

However, less than half (44.8%) of caregivers thought that outdoor caregiving they are providing caused stigmata or social intimidation.

Table 4 shows the results of PHQ-9 and GAD-7 scales. For PHQ-9, caregivers reported that 5 out of the 9 depressive symptoms did not bother them at all during the last 2 weeks while the remaining 4 depressive symptoms bothered them several days during the last 2 weeks. For example, almost all (98.9%) caregivers had no thoughts that they would be better off dead or hurting themselves but the majority (76.3%) were feeling tired or having little energy several days during the last 2 weeks. None of the 9 depressive symptoms was reported by the majority of the caregivers as bothering them more than half of the days nor nearly every day. For the GAD-7, caregivers reported that 4 out of the 7 anxiety symptoms bothered them several days during the last 2 weeks while the remaining 3 anxiety symptoms did not bother at all during the last 2 weeks. For example, the majority (76.3%) had trouble relaxing several days during the last 2 weeks but the majority (69.9%) did not at all feel being unable to stop or control worrying. None of the 7 anxiety symptoms was reported by the majority of the caregivers as bothering them more than half of the days nor nearly every day.

The PHQ-9 score among the caregivers ranged between 0 and 14 with an average of 4.3±2.7 points while GAD-7 score among the caregivers ranged between 0 and 20 with an average of 4.1±3.0 points. As shown in Figure 1, approximately 53.8% (50/93) of the caregivers had mild depression (PHQ-9 score between 5 and 9), 1.1% (1/93) had moderate depression (PHQ-9 score between 10 and 19), and none (0/93) had severe depression (PHQ-9 score between 20 and 27). Additionally, approximately 40.9% (38/93) of the caregivers had mild anxiety (GAD-7 score between 5 and 9), 1.1% (1/93) had moderate anxiety (GAD-7 score between 10 and 14), and 1.1% (1/93) had severe anxiety (GAD-7 score between 15 and 21). Considering the clinical

cutoff point (i.e. PHQ-9 or GAD-7 ≥10), the prevalence was 1.1% for depression, 2.2% for anxiety, and 2.2% for depression or anxiety. Including mild depression or anxiety (i.e. PHQ-9 or GAD-7 ≥5), the prevalence was 54.8% for depression, 43.0% for anxiety, and 59.1% for depression or anxiety. As shown in Figure 2, the majority of caregivers (64.8%) reported that the depressive symptoms were somewhat difficult while only 4.4% reported that these symptoms were very or extremely difficult as regards doing work, taking care of the things at home, or getting along with other people. Similarly, the majority of caregivers (62.4%) reported that the anxiety symptoms were somewhat difficult while only 5.4% reported that these symptoms were very or extremely difficult as regards doing work, taking care of the things at home, or getting along with other people.

Table 5 compared the caregivers' socio-demographic and clinical characteristics by the presence of depression or anxiety (including mild forms) among caregivers. Married caregivers represented 87.0% of those who had depression or anxiety compared with 100% of those who did not have depression or anxiety (p=0.039). With the exception of marital status, there were no significant associations between the caregivers' characteristics and the presence of depression or anxiety among them. Table 6 compared the socio-demographic and clinical characteristics of the family members with disability by the presence of depression or anxiety (including mild forms) among caregivers. There were trends of associations between caregivers' depression or anxiety and mental/intellectual disability (p=0.096), lack of other diseases (p=0.063), and the presence of moderate difficulty in accessing medical services (p=0.066). However, none of these or other characteristics were significantly associated with the presence of depression or anxiety among caregivers. Table 7 compared the characteristics of caregiving and its impact on the caregiver by the presence of depression or anxiety (including mild forms) among caregivers. There were

significant associations between the presence of depression or anxiety among caregivers and the feeling that family member with disability represent a source of stress for the family (75.0% versus 36.8%, $p<0.001$), the feeling that caregiving affect the ability to travel, work, or entrain (75.5% versus 63.2%, $p=0.047$), and the feeling that outdoor caregiving causes stigmata or social intimidation (57.1%versus 28.9%, $p=0.009$).

Table 8 shows univariate and multivariate logistic regression analysis of potential predictors of depression or anxiety (including mild forms) among caregivers. The characteristics that showed significant ($p<0.05$) or nearly significant ($p<0.10$) associations with depression or anxiety among caregiver (as shown in Tables 5 through 7) were examined. These included marital status of caregivers, type of disability and presence of other diseases among family member with disability, the difficulty of accessing medical services, the caregiver feeling that family members with disability represent a source of stress for the family, the caregiver feeling that caregiving affects the ability to travel, work, or entrain, and the caregiver feeling that outdoor caregiving causes stigmata or social intimidation. In multivariate analysis, the caregiver feeling that family members with disability represent a source of stress for the family was the only independent predictor of the presence of depression or anxiety among caregivers (odds ratio=7.79, 95% confidence 2.08-29.17, $p=0.002$) after adjusting for the above characteristics. Since there were no non-married caregivers among those who had no depression or anxiety, marital status among caregivers was removed from multivariate analysis to avoid model instability.

Table 1: Socio- demographic and clinical characteristics of the caregivers (N=93)

Variable	Value*	Variable	Value*
Age (years)		**Type of residence**	
Mean±SD	35.1±8.7	Owner	42 (45.7%)
<30	29 (31.9%)	Rent	48 (52.2%)
30-40	40 (44.0%)	Provided by employer	2 (2.2%)
>40	22 (24.2%)	**Number of rooms**	
Gender		Mean±SD	6.3±2.3
Male	2 (2.2%)	≤5	38 (42.7%)
Female	91 (97.8%)	≥6	51 (57.3%)
Nationality		**Number of family members**	
Saudi	73 (84.9%)	Mean±SD	5.9±2.3
Non-Saudi	13 (15.1%)	≤5	45 (48.9%)
Marital status		≥6	47 (51.1%)
Not married	7 (7.6%)	**Chronic disease**	
Married	85 (92.4%)	No	83 (89.2%)
Education		Yes	10 (10.8%)
Illiterate	11 (12.1%)	**Chronic disease, types**	
Primary school	2 (2.2%)	Hypertension	5 (50.0%)
Middle school	17 (18.7%)	Diabetes	3 (30.0%)
High school	25 (27.5%)	Others	2 (20.0%)
University	31 (34.1%)	**Regular medical checkup**	
Others	5 (5.5%)	No	60 (65.9%)
Occupation		Yes	31 (34.1%)
Governmental employee	13 (14.1%)	**Regular social activities**	
Private employee	3 (3.3%)	No	36 (39.1%)
Housewives/unemployed	75 (81.5%)	Yes	56 (60.9%)
Retired	1 (1.1%)	**Relation with family member with disability**	
Monthly family income (SR)		Mother	86 (91.4%)
<3,000	7 (7.5%)	Father	2 (2.2%)
3,000-5,999	21 (22.6%)	Son/daughter	3 (3.3%)
6,000-9,999	22 (23.7%)	Others	2 (2.2%)
10,000-14,999	14 (15.1%)	Husband/wife	1 (1.1%)
≥15,000	29 (31.2%)		

* Unless mentioned otherwise, number and percentage

Table 2: Socio- demographic and clinical characteristics of the family members with disability (N=93)

Variable	Value*	Variable	Value*
Age (years)		**Duration of disability (years)**	
Mean±SD	10.2±13.1	Mean±SD	6.4±7.8
Pre-school children (<6)	41 (44.6%)	<5	25 (39.1%)
School children (6-15)	39 (42.4%)	5-9	32 (50.0%)
Adult (>15)	12 (13.0%)	≥10	7 (10.9%)
Gender		**Level of disability**	
Male	65 (70.7%)	Mild	32 (34.8%)
Female	27 (29.3%)	Moderate	55 (59.8%)
Nationality		Severe	5 (5.4%)
Saudi	79 (85.9%)	**Other disease**	
Non-Saudi	13 (14.1%)	No	79 (86.8%)
Order among siblings		Yes	12 (13.2%)
Mean±SD	3.4±2.7	**Regular medical checkup**	
First	23 (27.1%)	No	46 (50.5%)
Second/third	30 (35.3%)	Yes	45 (49.5%)
Fourth or more	32 (37.6%)	**Accessibility to medical services**	
Parents consanguinity		Easy	53 (58.2%)
No	46 (50.5%)	Moderate	37 (40.7%)
Yes	45 (49.5%)	Difficult	1 (1.1%)
Type of disability			
Mental/intellectual	38 (40.9%)		
Speech/hearing	35 (37.6%)		
Physical	5 (5.4%)		
Psychiatric	5 (5.4%)		
Vision	2 (2.2%)		
Others	5 (5.4%)		
Multiple	3 (3.2%)		

* Unless mentioned otherwise, number and percentage

Table 3: Characteristics of caregiving and its impact (N=93)

Variable	Value*	Variable	Value*
Caregiving years		**Assistive devices for the family member with disability**	
Mean±SD	5.5±3.6	No	82 (92.1%)
<5	36 (43.4%)	Yes	7 (7.9%)
5-9	40 (48.2%)	**Type of assistive devices**	
≥10	7 (8.4%)	Hearing aids	3 (37.5%)
Caregiving hours per day		Wheelchairs	2 (25.0%)
Mean±SD	6.0±5.7	Glasses	2 (25.0%)
≤3	28 (31.8%)	Bathroom aids or diapers	1 (12.5%)
4-5	29 (33.0%)	**Social support for the family member with disability**	
>5	31 (35.2%)	No	40 (44.4%)
Another family member needs assistance		Yes	50 (55.6%)
No	76 (82.6%)	Specialized groups	30 (33.3%)
Yes	16 (17.4%)	Religious groups	13 (14.4%)
Reason another family member needs assistance		Others	7 (7.8%)
Disability	11 (73.3%)	**Recreational activities for the family member with disability**	
Elderly	3 (20.0%)	No	37 (41.6%)
Chronic disease	1 (6.7%)	Yes	52 (58.4%)
Another family member help in caregiving for the disabled		**Family member with disability represents stress for the family**	
No	11 (12.0%)	No	37 (41.1%)
Yes	81 (88.0%)	Yes	53 (58.9%)
Rehabilitation care services for the family member with disability		**Family member with disability affects your ability to**	
No	37 (40.7%)	None	27 (29.7%)
Yes	54 (59.3%)	Work	21 (23.1%)
Good communication with rehabilitation doctor/nurse		Travel	35 (38.5%)
No	13 (14.3%)	Entertain	8 (8.8%)
Yes	78 (85.7%)	**Outdoor caregiving causes stigmata or social intimidation**	
Good communication with rehabilitation social worker		No	48 (55.2%)
No	86 (96.6%)	Yes	39 (44.8%)
Yes	3 (3.4%)		

* Unless mentioned otherwise, number and percentage

Table 4: Results of Patient Health Questionnaire (PHQ-9) and Generalized Anxiety Disorder 7-item (GAD-7) scale among caregivers (N=93)

Variable	Not at all	Several Days	More than half the days	Nearly Every day
Patient Health Questionnaire (PHQ-9)				
1. Little interest or pleasure in doing things	49 (55.1%)	38 (42.7%)	2 (2.2%)	0 (0.0%)
2. Feeling down, depressed, or hopeless	29 (31.5%)	59 (64.1%)	3 (3.3%)	1 (1.1%)
3. Trouble falling asleep or sleeping too much	38 (40.9%)	53 (57.0%)	2 (2.2%)	0 (0.0%)
4. Feeling tired or having little energy	18 (19.4%)	71 (76.3%)	4 (4.3%)	0 (0.0%)
5. Poor appetite or overeating	48 (51.6%)	44 (47.3%)	1 (1.1%)	0 (0.0%)
6. Feeling bad about yourself- or that you are a failure or have let yourself or family down	40 (43.0%)	52 (55.9%)	1 (1.1%)	0 (0.0%)
7. Trouble concentrating on things, such as reading the newspaper or watching television	58 (63.0%)	33 (35.9%)	1 (1.1%)	0 (0.0%)
8. Moving or speaking so slowly that other people could have noticed. Or the opposite-being so fidgety or restless that you have been moving around a lot more than usual	80 (86.0%)	13 (14.0%)	0 (0.0%)	0 (0.0%)
9. Thoughts that you would be better off dead, or of hurting yourself in some way	92 (98.9%)	1 (1.1%)	0 (0.0%)	0 (0.0%)
Generalized Anxiety Disorder 7-item (GAD-7) scale				
1. Feeling nervous, anxious, or on edge?	31 (33.3%)	59 (63.4%)	2 (2.2%)	1 (1.1%)
2. Not being able to stop or control worrying?	65 (69.9%)	26 (28.0%)	1 (1.1%)	1 (1.1%)
3. Worrying too much about different things?	36 (38.7%)	54 (58.1%)	2 (2.2%)	1 (1.1%)
4. Trouble relaxing?	22 (23.7%)	69 (74.2%)	1 (1.1%)	1 (1.1%)
5. Being so restless that it is hard to sit still?	55 (60.4%)	34 (37.4%)	1 (1.1%)	1 (1.1%)
6. Becoming easily annoyed or irritable?	25 (26.9%)	65 (69.9%)	1 (1.1%)	2 (2.2%)
7. Feeling afraid as if something awful might happen?	58 (62.4%)	32 (34.4%)	2 (2.2%)	1 (1.1%)

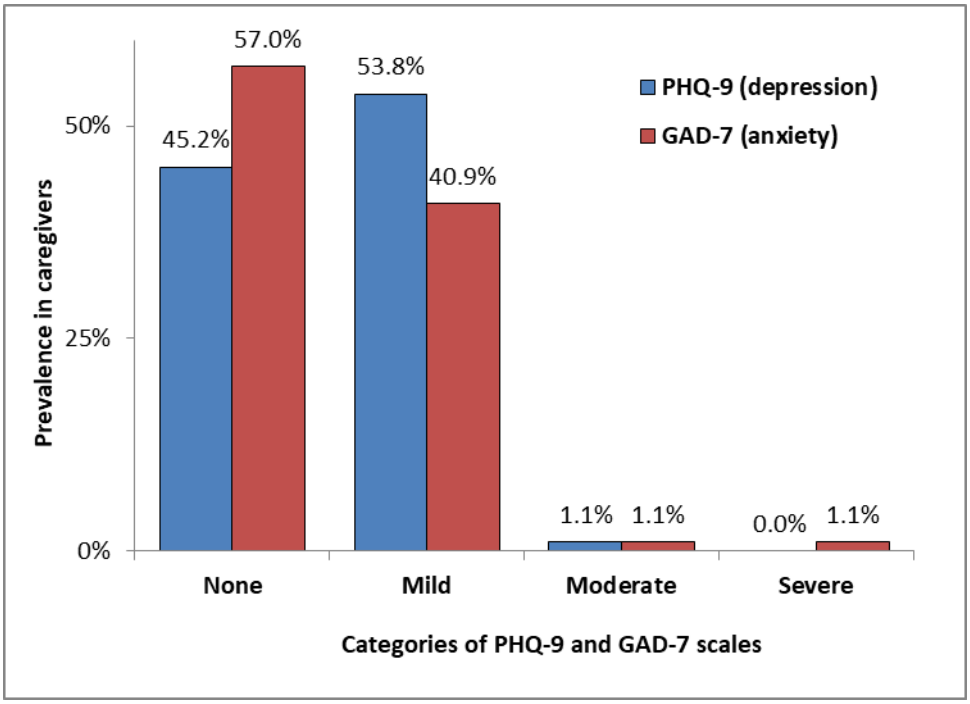

Figure 1: Prevalence of different levels depression and anxiety among the caregivers (N=93)

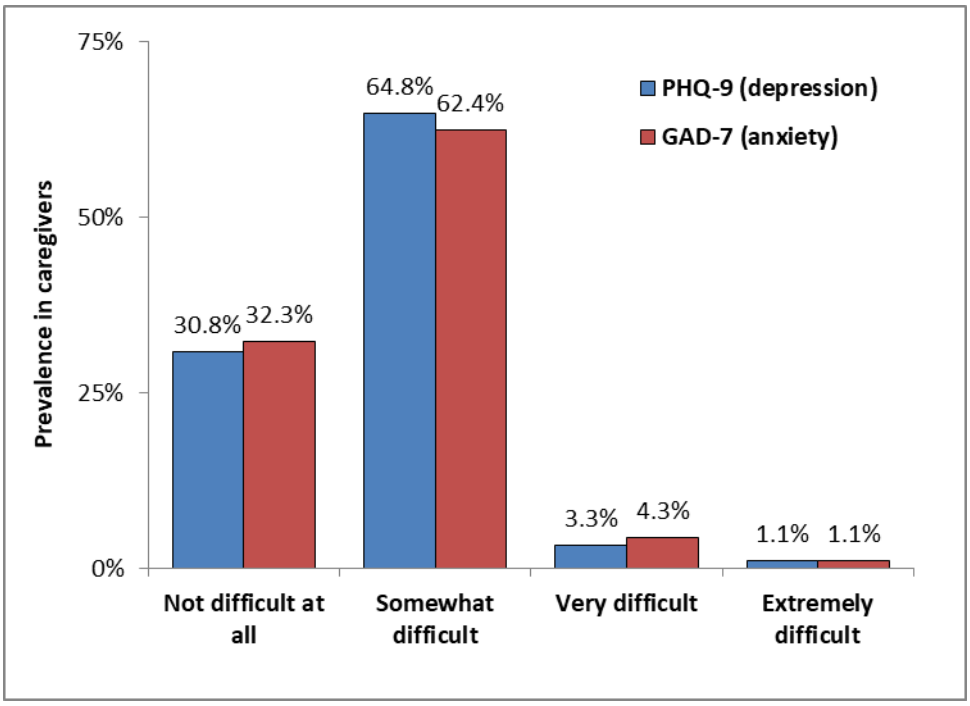

Figure 2 depressive symptoms'Functional impact of PHQ9' and GAD-7 anxiety symptoms among the caregivers (N=93)

Table 5: Socio- demographic and clinical characteristics of the caregivers by the presence of depression or anxiety (including mild forms) among caregivers (N=93)

	Depression or anxiety		p-value
	No (N=38)	Yes (N=55)	
Age (years)			
<30	11 (28.9%)	18 (34.0%)	0.162
30-40	14 (36.8%)	26 (49.1%)	
>40	13 (34.2%)	9 (17.0%)	
Gender			
Male	2 (5.3%)	0 (0.0%)	0.164
Female	36 (94.7%)	55 (100.0%)	
Nationality			
Saudi	31 (88.6%)	42 (82.4%)	0.429
Non-Saudi	4 (11.4%)	9 (17.6%)	
Marital status			
Not married	0 (0.0%)	7 (13.0%)	0.039
Married	38 (100.0%)	47 (87.0%)	
Education			
Less than high school	14 (38.9%)	16 (29.1%)	0.623
High school	9 (25.0%)	16 (29.1%)	
Graduate/others	13 (36.1%)	23 (41.8%)	
Occupation			
Not working	33 (86.8%)	43 (79.6%)	0.369
Working	5 (13.2%)	11 (20.4%)	
Monthly family income (SR)			
<6,000	12 (31.6%)	16 (29.1%)	0.752
6,000-14,999	13 (34.2%)	23 (41.8%)	
≥15,000	13 (34.2%)	16 (29.1%)	
Type of residence			
Not-owner	21 (55.3%)	29 (53.7%)	0.882
Owner	17 (44.7%)	25 (46.3%)	
Number of rooms	6.1±2.4	6.4±2.2	0.564
Number of family members	6.2±2.2	5.7±2.4	0.290
Chronic disease			
No	32 (84.2%)	51 (92.7%)	0.307
Yes	6 (15.8%)	4 (7.3%)	
Regular medical checkup			
No	24 (64.9%)	36 (66.7%)	0.859
Yes	13 (35.1%)	18 (33.3%)	
Regular social activities			
No	13 (35.1%)	23 (41.8%)	0.520
Yes	24 (64.9%)	32 (58.2%)	
Relation with family member with disability			
Mother	32 (86.5%)	52 (94.5%)	0.260
Others	3 (13.5%)	3 (5.5%)	

Table 6: Socio- demographic and clinical characteristics of the family member with disability by the presence of depression or anxiety (including mild forms) among caregivers (N=93)

	Depression or anxiety		p-value
	No (N=38)	Yes (N=55)	
Age			
Pre-school children (<6)	14 (37.8%)	27 (49.1%)	0.340
School children (6-15)	16 (43.2%)	23 (41.8%)	
Adult (>15)	7 (18.9%)	5 (9.1%)	
Gender			
Male	24 (64.9%)	41 (74.5%)	0.317
Female	13 (35.1%)	14 (25.5%)	
Nationality			
Saudi	34 (91.9%)	45 (81.8%)	0.174
Non-Saudi	3 (8.1%)	10 (18.2%)	
Order among siblings			
First	7 (19.4%)	16 (32.7%)	0.239
Second/third	16 (44.4%)	14 (28.6%)	
Fourth or more	13 (36.1%)	19 (38.8%)	
Parents consanguinity			
No	15 (40.5%)	31 (57.4%)	0.114
Yes	22 (59.5%)	23 (42.6%)	
Type of disability			
Mental/intellectual	13 (34.2%)	25 (45.5%)	0.096
Speech/hearing	18 (47.4%)	17 (30.9%)	
Physical	3 (7.9%)	2 (3.6%)	
Psychiatric	0 (0.0%)	5 (9.1%)	
Vision	2 (5.3%)	0 (0.0%)	
Others	1 (2.6%)	4 (7.3%)	
Multiple	1 (2.6%)	2 (3.6%)	
Duration of disability*	5.6±2.6	7.0±10.0	0.507
Level of disability			
Mild	15 (39.5%)	17 (31.5%)	0.400
Moderate	20 (52.6%)	35 (64.8%)	
Severe	3 (7.9%)	2 (3.7%)	
Other disease			
No	29 (78.4%)	50 (92.6%)	0.063
Yes	8 (21.6%)	4 (7.4%)	
Regular medical checkup			
No	19 (50.0%)	27 (50.9%)	0.929
Yes	19 (50.0%)	26 (49.1%)	
Accessibility to medical services			
Easy	27 (71.1%)	26 (49.1%)	0.066
Moderate	11 (28.9%)	26 (49.1%)	
Difficult	0 (0.0%)	1 (1.9%)	

Table 7: Characteristics of caregiving and its impact by the presence of depression or anxiety (including mild forms) among caregivers (N=93)

	Depression or anxiety		p-value
	No (N=38)	Yes (N=55)	
Caregiving years*	5.7±2.5	5.3±4.2	0.186
Caregiving hours per day*	6.7±6.6	5.5±5.0	0.194
Another family member needs assistance			
No	34 (89.5%)	42 (77.8%)	0.145
Yes	4 (10.5%)	12 (22.2%)	
Another family member help in caregiving for the family member with disability			
No	4 (10.5%)	7 (13.0%)	>0.99
Yes	34 (89.5%)	47 (87.0%)	
Rehabilitation care services for the family member with disability			
No	16 (42.1%)	21 (39.6%)	0.812
Yes	22 (57.9%)	32 (60.4%)	
Good communication with rehabilitation doctor/nurse			
No	7 (18.4%)	6 (11.3%)	0.340
Yes	31 (81.6%)	47 (88.7%)	
Good communication with rehabilitation social worker			
No	36 (97.3%)	50 (96.2%)	>0.99
Yes	1 (2.7%)	2 (3.8%)	
Assistive devices for the family member with disability			
No	33 (89.2%)	49 (94.2%)	0.443
Yes	4 (10.8%)	3 (5.8%)	
Social support for the family member with disability			
No	15 (39.5%)	25 (48.1%)	0.417
Yes	23 (60.5%)	27 (51.9%)	
Recreational activities for the family member with disability			
No	15 (39.5%)	22 (43.1%)	0.729
Yes	23 (60.5%)	29 (56.9%)	
Family member with disability represents stress for the family			
No	24 (63.2%)	13 (25.0%)	<0.001
Yes	14 (36.8%)	39 (75.0%)	
Family member with disability affects your ability to			
None	14 (36.8%)	13 (24.5%)	0.047
Work	4 (10.5%)	17 (32.1%)	
Travel	18 (47.4%)	17 (32.1%)	
Entertain	2 (5.3%)	6 (11.3%)	
Outdoor caregiving causes stigmata or social intimidation			
No	27 (71.1%)	21 (42.9%)	0.009
Yes	11 (28.9%)	28 (57.1%)	

Table 8: Multivariate logistic regression analysis of potential predictors of the presence of depression or anxiety (including mild forms) among caregivers (N=93)

	Reference	Odds ratio	95% confidence interval		p-value
			Lower	Upper	
Univariate analysis					
Married caregiver	Non-married	0.0	0.0	0.0	0.999
Type of disability					
Mental/intellectual	Other disability	1.04	0.33	3.23	0.952
Speech/hearing	Other disability	0.51	0.16	1.58	0.242
Other disease in family member with disability	Lack of disease	0.29	0.08	1.05	0.059
Moderate/difficult accessibility to medical services	Easy accessibility	2.55	1.05	6.17	0.038
Family members with disability represent a source stress for the family	Not stressful	5.14	2.07	12.78	<0.001
Family members with disability affect ability to work, travel, or entertain	Not affecting	1.80	0.72	4.45	0.207
Outdoor caregiving causes stigmata or social intimidation	Not causing	3.27	1.33	8.06	0.010
Multivariate analysis*					
Family members with disability represent a source stress for the family	Not stressful	7.79	2.08	29.17	0.002

*Adjusted for all factors shown in univariate analysis above with the exception of marital status among caregiver which caused model instability (due to zero odds ratio)

** Model R-square = 0.263

DISCUSSION

This study report a mild degree of depression and anxiety among caregivers (mainly mothers) who were providing caregiving for family members with disability (mainly their children) and attending one of two rehabilitation clinics at the Eastern Saudi Arabia. Considering the clinical cutoff point suggested before for the diagnosis of depression or anxiety using PHQ-9 and GAD-7 (≥10) [56, 57], the prevalence was 1.1% for depression, 2.2% for anxiety, and 2.2% for depression or anxiety. When we included mild depression or anxiety (i.e. PHQ-9 or GAD-7 ≥5), the prevalence became 54.8% for depression, 43.0% for anxiety, and 59.1% for depression or anxiety. Since in this study found only two caregivers who had depression or anxiety as per the clinical cutoff points, This study decided to consider groups needed to compare risk factors based on the second liberal definition (i.e. after including mild depression or anxiety).

Previous studies done internationally among mothers providing caregiving for children with intellectual disability, learning disability, and epilepsy showed that the prevalence of depression was between 10% and 50% using appropriate clinical cutoff points [31-33] and the prevalence of anxiety was approximately 25% using appropriate clinical cutoff point [33]. Although the prevalence of depression and anxiety among caregivers was not reported in similar studies done previously in Saudi Arabia [41, 42], the level of depression and anxiety scores reported in the current and previous local studies were generally comparable. For example, in the current study, the average PHQ-9 and GAD-7 scores were 4.3 and 4.1 (respectively, out of a maximum of 21 points) while in the local similar studies, the average HAD scales were 5.4-9.5 for depression and 4.9-10.5 for anxiety (out of a maximum of 21 points). Interestingly, the cutoff point for the diagnosis of clinical depression or anxiety in all these tests is ≥10. Although the

authors of these studies did not calculated prevalence, it seems that the prevalence rates (≥10) would be comparable.

The current prevalence rates seem much lower than the rates reported internationally when considering the clinical cutoff point [31-33]. While it is difficult to give single definitive explanation, this big difference may reflect cultural and other healthcare differences. Several factors common in the Saudi culture are believed to strengthen the mother and family in coping with the burden of the disabled child. For example, Islamic teaching stress that facing life hardships, obstacles, and struggle should be generously rewarded by God in many aspects [11]. Additionally, extended family support and social support is very common [61]. Actually, close to 90% of caregivers in the current study had another family member who is helping in caregiving for the same family member with disability. Finally, caregiving is observed as a normal mother role which makes institutional caregiving is very uncommon or very unacceptable. On the other hand, additional healthcare factors may positively impact mothers. For example, healthcare services in Saudi Arabia are largely covered by the government for all Saudi nationals which may limit the financial impact on families with disabled members. Additionally, the majority of our caregivers had good communication with rehabilitation doctor/nurse, which has been reported to effectively reduce the risk for depression among caregiving mothers [38]. Nevertheless, comparing the prevalence from current study with previous studies is not an easy task. This is primarily due to different tools used for the diagnosis of depression and anxiety, different cutoff points suggested for diagnosis, and obviously different population examined including caregivers and family member with disability. For example, in the review study that examined 17 studies done among mothers providing caregiving for children with epilepsy, the authors reported several tools used in the assessment of depressive symptoms such as Beck Depression Inventory (BDI), General Health Questionnaire (GHQ), and Hospital Anxiety and Depression Scale (HAD) [31].

Additionally, a number of studies never report the prevalence but rather reported the actual score of the tool used [31]. The later has been seen in the studies done in Saudi Arabia [41, 42] as well as some studies done internationally [31, 45, 49].

The predictors of depression or anxiety (even of mild degree) among caregivers in the current study were largely associated with the characteristics of the caregivers rather than the disabled child. For example, in univariate analysis, caregivers' feeling that family members with disability represent a source of stress for the family, affect the ability to do daily activities, and represent a source of stigmata or social intimidation were associated with the presence of depression or anxiety (even of mild degree) among caregivers. In multivariate analysis, the caregiver feeling that family member with disability represent a source of stress for the family was the only independent predictor for the presence of depression or anxiety among caregivers. The finding may indicate the importance of providing support to alleviate the family stress. Previous studies done outside Saudi showed that maternal depression is associated with several caregivers characteristics such as maternal role ambiguity or worry, neuroticism, lower education levels, insufficient income, family problems, and being a single mother [31, 32, 45-47]. Additionally, some disabled child characteristics have been reported to be linked to maternal depression such as presence of comorbidities and behavior problems [31]. Maternal anxiety was linked in few studies to family need items and disabled child recovery [48, 49]. On the other hand, some studies failed to detect a link between maternal depression or anxiety and several child or maternal predictors [31, 49]. For example, maternal depression among mothers providing caregiving for children with epilepsy was not associated with any maternal or child characteristics, with the exception of the presence of behavior problems in the disabled child [62]. Additionally, maternal anxiety and depression among mothers of infants with perinatal brachial plexus injury was not associated with the severity of disability [49]. In several cases, the

failure to detect predictors can be attributed to lack of statistical power rather than a true absence of associations [31].

The most common types of disability in our study were mainly mental/intellectual disability and speech/hearing disability. This finding should not be an accurate indicator for the prevalence of different types of disability in a typical Saudi community. This may be caused by the fact that not all rehabilitation clinics serve all types of patients, which is dependent on their setting. In our clinics, the majority of the population served are those with speech or developmental delay, Down syndrome, ADHD, and cerebral palsy. According to national data, the most common types of disability in Saudi Arabia are physical, vision, and hearing disability while mental disability comes at the bottom of the list [4]. On the other hand, the mental disability were shown in cross-sectional studies to be as common as physical disability [18] or at least among the top ones [13, 16].

The risk factors that have been frequently linked with disability among Saudi children included early- and late-age marriage or childbearing, multi-parity, consanguineous marriages, illiteracy, and unemployment [14, 15]. Similarly, we observed in the current study that approximately half of family members with disability had parents' consanguinity, more than 80% of caregivers were not working, approximately a third of the caregivers had education below high school, and living with large-sized families (average 5.9 members). Nevertheless, since our study design did not include a control group, we can not claim that any of the above factors was really linked to the development of disability in the examined disabled person

STUDY STRENGTH AND LIMITATIONS

The current study had several strengths and few limitations. The current study is considered the first in Saudi to estimate the prevalence of depressive and anxiety symptoms among caregivers who are providing caregiving for family members with disability at primary care rehabilitation setting. Additionally, we assessed depression and anxiety using previously validated Arabic version of standard tools. Moreover, we collected extensive data about the caregivers and the family members with disability to detect potential associations. Nevertheless, we acknowledge some limitations. For example, the convenience sampling within the chosen population and the different disability profile in different rehabilitation clinics in Saudi Arabia may limit the generalizability of the current findings. Additionally, as the study used a cross-sectional design, causal association cannot be confirmed for any factors using univariate or multivariate analysis. However, these limitations are almost unavoidable in all similar studies which examined the prevalence of psychological problems among caregivers. Finally, while the sample size in the current study was considered sufficient to estimate the prevalence of depressive and anxiety symptoms among caregivers, it may be insufficient to detect some weaker associations.

CONCLUSIONS AND RECCOMMENDATIONS

The findings of the current study revealed mild degrees of depression and anxiety among caregivers (mainly mothers) who were providing caregiving for family members with disability (mainly their children) and attending one of two rehabilitation clinics at the Eastern Saudi Arabia. Considering the clinical cutoff point, the current prevalence rates seem much lower than the rates reported internationally. While it is difficult to give a definitive explanation, the difference may reflect cultural and other healthcare differences. The predictors of depression or anxiety (even of mild degree) among caregivers in the current study were largely associated with the characteristics of the caregivers rather than the disabled child. Out of associated variables in univariate analysis, the caregiver feeling that family members with disability represent a source of stress for the family was the only independent predictor for the presence of depression or anxiety among caregivers.

Based on the current study findings, the following strategies are suggested to improve our understanding of the burden of the problem and to minimize the impact of caregiving on mothers providing caregiving for children with disability:

- We need to conduct large multicenter studies covering different geographical regions in Saudi Arabia to better estimate the psychological burden of caregiving on families with family members with disability. These large-sized studies can answer several additional research questions;
    - Other psychological burden outcomes such as stress, burnout, and quality of life
    - Variability of the psychological burden in different types of disability
    - Geographic variation in psychological burden of caregiving

- The social support received by families with disabled people at rehabilitation clinics need more attention as the majority of the caregivers in this study had no good communications with the attached social workers and approximately 45% had no access to any social support so building a strong well design reporting program in primary health center registered caregivers of each family with multidisciplinary contact to social and psychological services
- As the majority of the caregivers in ours study had good communications with rehabilitation doctor/nurse, this bond needs to be invested in offering structured educational programs aiming to reduce the psychological burden among caregiving mothers
- Increasing the awareness of the community with modifiable risk factors that have been linked to child disability such as early- and late-age marriage or childbearing, multi-parity, consanguineous marriages, illiteracy may be important
- Initiating a multiple campaign supporting program especially in rular and villages areas which are difficult to reach such as ares with high attitude ((mountain areas)) under direct governmental supervision can provide a lot of help and decrease the burden over caregivers members using the electronic pattern services which facilitate the communications between the different region of Saudia Arabia province

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APPENDIX I: CONSENT FORM

English Version

Serial Number: ----------

Consent Form

You are doing a great job by caring one of you family members but long term caregiving may lead to strains to some caregivers. I am pleased to invite you to participate in this research, which aims to assess the burden of psychological problems among caregivers who are providing caregiving for family members with disability. Your response may help us to assess the burden of the problem which is a critical step for planning and implementation of any future intervention programs targeting people like you. You are expected to answer the questions of the study questionnaire in about 20 minutes. Acceptance of participation is completely voluntarily, without any impact on your provided service at this rehabilitation clinic. Signing this consent were considered your acceptance of participation. The researcher is committed to secure the confidentiality of your information which is completely anonymous and using it only for the purpose of this research. Please do not hesitate to contact me for any related questions or concerns or to get summary of the research results.

Thank you,

Ebtisam Al-Rowdhan

Mobile: 0504982637

Email: ebtisam.rowdhan@gmail.com

Signature:

Date: / /

Arabic Version

الرقم التسلسلي: ----------

استمارة الموافقة على المشاركة فى بحث

نعلم أنكم تقومون بعمل عظيم برعاية شخص معاق من أفراد عائلتك ولكن الرعاية طويلة الأجل قد تؤدي إلى بعض الضغوط النفسية لبعض مقدمي الرعاية. يسرني أن أدعوكم إلى المشاركة في هذا البحث، الذي يهدف إلى تقييم مدى وجود و مستوى المشاكل النفسية بين مقدمي الرعاية لشخص معاق من أفراد العائلة. إن استجابتك للمشاركة في هذا البحث قد تساعدنا على تقييم حجم هذه المشكلة وقد تكون خطوة ضرورية لتخطيط وتنفيذ برامج الوقاية لأشخاص مثلك فى المستقبل. يتوقع ان تستطيع الانتهاء من الإجابة على أسئلة الاستبيان الخاص بالدراسة في حوالي 20 دقيقة. قبولك المشاركة في هذا البحث هي عملية طوعية تماما، دون أي تأثير على شكل او مستوي الخدمة المقدمة للشخص المعاق في عيادة اعادة التأهيل. توقيعك على هذه الاستمارة سوف تعتبر موافقتك على المشاركة في هذا البحث. الباحثة المسؤلة عن هذا البحث ملتزمة بضمان سرية المعلومات الخاصة بك والتى ستكون مجهول تماما للاخرين كما ان المعلومات لن تستخدم إلا لغرض هذا البحث الموضح اعلاه. لا تترددوا في الاتصال بي لأي استفسار يتصل بهذا البحث أو الحصول على ملخص لنتائج البحث بعد الانتهاء منه

ولكم مني جزيل الشكر

د/ ابتسام الروضان

موبيل رقم0504982637

البريد الاكتروني:ebtisam.rowdhan@gmail.com

ألتوقيع: ----------

التاريخ: / / 2017

APPENDIX II: QUESTIONNAIRE

English Version

1. **Serial Number:** ----------
2. **Date:** ------/-------/-----------

I- Information about you:

3. **Age:** ---------- years
4. **Gender**
    - Male
    - Female
5. **Nationality**
    - Saudi
    - Non-Saudi; Specify: ……
6. **Marital status**
    - Single
    - Married
    - Divorced/separated
    - Widow
7. **Education**
    - Illiterate
    - Primary school
    - Middle School
    - High School
    - College
    - Post-graduate
    - Others: ----------
8. **Occupation:**

- ○ Governmental employee
- ○ Private employee
- ○ Unemployed including housewives
- ○ Retired
- ○ Students

9. Monthly family income

- ○ <3,000 SR
- ○ 3,000-5,999 SR
- ○ 6,000-9,999 SR
- ○ 10,000-14,999 SR
- ○ ≥15,000 SR

10. Type of residence

- ○ Owner
- ○ Rent
- ○ Provided by employer

11. Number of rooms ----------

12. Number of family members ----------

13. Do you have chronic disease

- ○ **No**
- ○ Yes

14. If yes, what chronic disease

- ○ Hypertension
- ○ Diabetes
- ○ Asthma or other chronic respiratory disease
- ○ Heart disease
- ○ Renal failure

- ○ Liver failure
- ○ Cancer
- ○ Others; ----------

15. Do you have regular medical checkup

- ○ No
- ○ Yes

16. Do you have regular social activities such as gem, salon, social visit, or football match

- ○ No
- ○ Yes

17. Relation to the family member with disability

- ○ Father/mother
- ○ Husband/wife
- ○ Son/daughter
- ○ Brother/sister
- ○ Others,----------

II- Information about the family member with disability you care:

18. Age: ---------- years

19. Gender

- ○ Male
- ○ Female

20. Nationality

- ○ Saudi
- ○ Non-Saudi; Specify: ……

21. Order among brothers and sisters: ----------

22. Are parents consanguineous?

- ○ **No**
- ○ Yes

23. Type of disability (mark whatever applies)

- ○ Physical
- ○ Mental/intellectual
- ○ Sensory: speech/hearing
- ○ Sensory: vision
- ○ Psychiatric
- ○ Others, ----------

24. Duration of disability: ---------- years

25. Level of disability

- ○ Mild
- ○ Moderate
- ○ Severe

26. Does the family member with disability have other diseases?

- ○ No
- ○ Yes, specify: ----------

27. Does the family member with disability have regular medical checkup?

- ○ No
- ○ Yes

28. How easy for the family member with disability to reach and get access to medical services?

- ○ Easy
- ○ Moderate
- ○ Difficult

III- Information about caregiving and rehabilitation care:

29. Number of years of caregiving you provided: ----------

30. Average number of caregiving hours you provide per day: ----------

31. Do you have another member of the family who need assistance?

- ○ No
- ○ Yes, if yes, specify type
  - ○ Disability
  - ○ Elderly
  - ○ Psychiatric disease
  - ○ Chronic disease

32. Do other members of the family help you giving care to the family member with disability?

- ○ No
- ○ Yes

33. Does the family member with disability regularly receive rehabilitation care services?

- ○ No
- ○ Yes

34. Do you have good communication with attached rehabilitation doctor or nurse?

- ○ No
- ○ Yes

35. Do you have good communication with attached rehabilitation social worker?

- ○ No
- ○ Yes

36. Does the family member with disability regularly receive assistive devices?

- ○ No
- ○ Yes

37. If yes, what assistive devices received?

- ○ Wheelchairs
- ○ Walking aids: walkers, canes, or crutches,
- ○ Hearing aids
- ○ Glasses

- ○ Bathroom aids or diapers
- ○ Others, specify: ----------

38. Does the family member with disability receive social support?

- ○ None
- ○ Specialized groups
- ○ Religious groups
- ○ Campaigns
- ○ Others; specify: ----------

39. Is the family member with disability involved in recreational activities?

- ○ No
- ○ Yes; specify: ----------

IV- Information about the impact of caregiving:

40. Does the family member with disability represent stress for the family?

- ○ No
- ○ Yes

41. Does the caregiving you provide affect your ability to

- ○ Work
- ○ Travel
- ○ Entertain

42. Does the outdoor caregiving you provide cause stigmata or social intimidation?

- ○ No
- ○ Yes

Arabic Version

استبيان الدراسة

1. **الرقم التسلسلي:----------**
2. **التاريخ:-----/-----/----------**

أولا- بيانات مقدم الرعاية:

3. **العمر:----------** سنة
4. **الجنس:**
   - ذكر
   - أنثى
5. **الجنسية:**
   - سعودي
   - غير سعودي: ----------
6. **الحالة الاجتماعية:**
   - أعذب
   - متزوج
   - مطلق/منفصل
   - أرمل
7. **المستوى التعليمي:**
   - أمي
   - الابتدائي
   - الإعدادي
   - الثانوي
   - الكلية
   - الدراسات العليا
   - أخرى: ----------
8. **المهنة:**
   - موظف حكومي
   - موظف بالقطاع الخاص
   - لا يعمل بما في ذلك ربات البيوت
   - متقاعد
   - طالب
9. **دخل العائلة الشهري**
   - أقل من 3,000 ريال
   - 5,999-3,000 ريال
   - 9,999-6,000 ريال
   - 14,999 -10,000 ريال

- 15,000 ريال فأكثر

10.نوع السكن

- مالك
- إيجار
- يتم توفيره عن طريق العمل

11.عدد غرف السكن: ----------

12.عدد أفراد العائلة: ----------

13.هل تعانى من أمراض مزمنة؟

- لا
- نعم

14.إذا كانت الاجابة بنعم، ما هي هذه الأمراض المزمنة؟

- ارتفاع ضغط الدم
- السكري
- الربو أو الأمراض التنفسية المزمنة الأخرى
- أمراض القلب
- الفشل الكلوي
- فشل الكبد
- السرطان
- اخري: ----------

15.هل تحصل على فحص طبي منتظم؟

- لا
- نعم

16.هل لديك أنشطة اجتماعية مثل التمارين الرياضية ،والصالونات ، والزيارات الاجتماعية، و مبارايات كرة القدم ؟

- لا
- نعم

17.ما هي علاقتك بالشخص المعاق؟

- أب/أم
- زوج/زوجة
- ابن/ابنة
- أخ/أخت
- اخري: ----------

ثانيا- بيانات الشخص المعاق:

18.العمر:---------- سنة

19.الجنس:

- ذكر

- أنثى

20.الجنسية:

- سعودي
- غير سعودي: ----------

21.الترتيب بين الأخوة والأخوات:----------

22.هي الوالدين أقارب؟

- لا
- نعم

23.نوع الإعاقة (يمكن اختيار أكثر من اجابة)

- حركية
- عقلية
- في الكلام/السمع
- في النظر
- نفسية
- اخري: ----------

24.مدة الإعاقة: -------- سنوات

25.مستوى الإعاقة

- خفيف
- معتدل
- شديد

26.هل يعانى الشخص المعاق من أمراض مزمنة؟

- لا
- نعم: ----------

27.هل يحصل الشخص المعاق على فحص طبي منتظم؟

- لا
- نعم

28.مدى سهولة وصول و حصول الشخص المعاق علي الخدمات الطبية ؟

- سهلة
- متوسط السهولة
- صعبة

ثالثا- بيانات الرعاية وإعادة التأهيل للشخص المعاق:

29.عدد سنوات الرعاية التي قمت بتقديمها للشخص المعاق:----------

30.متوسط عدد ساعات تقديم الرعاية يوميا:----------

31.هل يوجد شخص أخر من أفراد عائلتك يحتاج إلى المساعدة؟

- لا
- نعم، السبب

- الإعاقة
- مسن
- الأمراض النفسية
- الأمراض المزمنة

32. هل هناك شخص أخر من أفراد عائلتك يساعدك فى تقديم الرعاية للشخص المعاق ؟

- لا
- نعم

33. هل يحصل الشخص المعاق على خدمات إعادة تأهيل منتظمة ؟

- لا
- نعم

34. هل لديك اتصالات جيدة مع مقدمي إعادة التأهيل كالطبيب أو الممرضة؟

- لا
- نعم

35. هل لديك اتصالات جيدة مع المشرف الاجتماعي لإعادة التأهيل ؟

- لا
- نعم

36. هل يحصل الشخص المعاق على معدات وأجهزة إعادة التأهيل بانتظام؟

- لا
- نعم

37. إذا كان الجواب نعم، ما هي المعدات و الأجهزة المساعدة المتلقاة؟

- كرسي متحرك
- مساعدات المشي كالعكازات
- سماعات للاذن
- نظارات
- مساعدات التبول و التبرز و الحفاضات
- اخري: ----------

38. هل يحصل الشخص المعاق علي دعم اجتماعي؟

- لا يحصل على دعم
- يحصل على دعم من جمعيات الاعاقة المتخصصة
- يحصل على دعم ديني
- يتم شمله فى الحملات التوعوية
- اخري: ----------

39. هل يشارك الشخص المعاق في الأنشطة الترفيهية؟

- لا
- نعم

رابعا- بيانات عن أثر تقديم الرعاية:

40. هل يمثل الشخص المعاق ضغطا أوعبئا علي العائلة؟

- ○ لا
- ○ نعم

41. هل تقديمك الرعاية للشخص المعاق يؤثر على قدرتك على

- ○ العمل
- ○ السفر
- ○ الترفيه

42. هل تقديمك الرعاية للشخص المعاق خارج المنزل يسبب لك الاحراج الاجتماعي؟

- ○ لا
- ○ نعم

APPENDIX III: PHQ-9

English Version
Patient Health Questionnaire (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several Days	More than half the days	Nearly Every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling asleep or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself- or that you are a failure or have let yourself or family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite-being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way	0	1	2	3
	Add Columns	_____	+ _____	+ _____

Total _____

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of the things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

Arabic Version
استبيان صحة المرضى-9

خلال الأسبوعين الماضيين، كم مرة عانيت من أي من المشاكل التالية؟ (ضع علامة **دائرة** حول اختيارك)	**ولا مرة**	**عدة أيام** (اقل من نصف الايام)	**اكثر من نصف الايام**	**تقريبا كل يوم**
1- قلة الاهتمام أو قلة الاستمتاع بممارسة بالقيام بأي عمل	0	1	2	3
2- الشعور بالحزن أو ضيق الصدر أو اليأس	0	1	2	3
3- صعوبة في النوم أو نوم متقطع أو النوم أآثر من المعتاد	0	1	2	3
4- الشعور بالتعب أو بامتلاك القليل جداً من الطاقة	0	1	2	3
5- قلة الشهية أو الزيادة في تناول الطعام عن المعتاد	0	1	2	3
6- الشعور بعدم الرضا عن النفس أو الشعور بأنك قد أخذلت نفسك أو عائلتك	0	1	2	3
7- صعوبة في التركيز مثلاً أثناء قراءة الصحيفة أو مشاهدة التلفزيون	0	1	2	3
8- بطء في الحركة أو بطء في التحدث عما هو معتاد لدرجة ملحوظة من الآخرين أو على العكس من ذلك التحدث بسرعة وكثرة الحركة أكثر من المعتاد	0	1	2	3
9- راودتك أفكار بأنه من الأفضل لو كنت ميتا أو أفكار بأن تقوم بإيذاء النفس	0	1	2	3

_____ + _____ + _____ + ___*0*___ = **Total Score:** _____ **(FOR OFFICE CODING)**

*إذا اشرت إلى **<u>أية</u>** من المشاكل اعلاه, فإلى أية درجة **<u>صعّبت</u>** عليك هذه المشاكل القيام بعملك, الاعتناء بالامور المنزلية, أو الانسجام مع أشخاص آخرين؟

1- ليست هناك اي صعوبة ☐ **2- هناك بعض الصعوبات** ☐ **3- هناك صعوبات شديدة** ☐ **4- هناك صعوبات بالغة التعقيد** ☐

APPENDIX IV: GAD-7

English Version
Generalized Anxiety Disorder 7-item (GAD-7) scale

Over the last 2 weeks, have you felt bothered by any of these things?	Not at all	Several Days	More than half the days	Nearly Every day
1. Feeling nervous, anxious, or on edge?	0	1	2	3
2. Not being able to stop or control worrying?	0	1	2	3
3. Worrying too much about different things?	0	1	2	3
4. Trouble relaxing?	0	1	2	3
5. Being so restless that it is hard to sit still?	0	1	2	3
6. Becoming easily annoyed or irritable?	0	1	2	3
7. Feeling afraid as if something awful might happen?	0	1	2	3

Add Columns _____ + _____ + _____

Total _____

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of the things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

Arabic Version
مقياس اضطراب القلق العام-7

خلال الأسبوعين الماضيين، كم مرة عانيت من أي من المشاكل التالية؟(ضع علامة **دائرة** حول اختيارك)	**ولا يوم على الاطلاق**	**أيام متعددة** (اقل من نصف الايام)	**أكثر من نصف الأيام**	**كل يوم تقريبا**
1. الشعور بالعصبية أو القلق أو التوتر	0	1	2	3
2. عدم القدرة على التوقف عن القلق أو السيطرة عليه	0	1	2	3
3. القلق الشديد بشأن أمور عديدة	0	1	2	3
4. مشاكل في الاسترخاء	0	1	2	3
5. أن تكون مضطربا لدرجة تجعلك غير قادر على الجلوس بهدوء	0	1	2	3
6. تستاء أو تغضب بسرعة	0	1	2	3
7. تشعر بالخوف من حصول امر رهيب	0	1	2	3

*إذا أشرت بعلامة إلى أي من المشاكل, إلى أي درجة جعلت هذه المشاكل الأمور التالية صعبة بالنسبة لك:

القيام بعملك أو تدبير أمور المنزل أو الانسجام مع الآخرين؟

1- ليست صعبة على الإطلاق ☐ **2- صعبة نوعا ما** ☐ **3- صعبة جدا** ☐ **4- صعبة إلى اقصى حد** ☐